A special needs trust can be an excellent tool to protect eligibility for public benefits and to provide financial support to a beneficiary. However, the trust itself doesn't provide much information about a beneficiary's needs or about how trust money should be spent. Without more information, a trustee who is taking over for a parent or another long-term caregiver may be left with little understanding about the beneficiary's disability, day-to-day needs, advocacy requirements, or how the trustee should spend trust funds.

A "letter of intent" (sometimes called a "memorandum of intent") is the best way to fill in the gaps that the special needs trust document doesn't cover. In the letter, you can explain your loved one's current needs, describe the care that he or she may need in the future, and lay out your wishes for how the trustee should spend trust funds. A letter of intent is not a required document—if you decide not to prepare one, the trust is still valid. But a letter of intent does provide an opportunity to leave critical information about your loved one to future caregivers. In fact, successor trustees may look at a letter of intent more frequently than the trust document itself, because it more fully addresses the financial and personal decisions caregivers have to make on a daily basis.

Preparing a letter of intent is a good idea even if the person who serves as successor trustee is the beneficiary's parent, sibling, other close relative, or friend who already has a deep understanding of the beneficiary's likes, dislikes, proclivities, habits, needs, and desires. If your successor trustee dies or becomes unavailable, your letter of intent helps ensure that whoever takes over will have a good understanding about how to proceed. Also, time can cloud or confuse memory, so if you have any specific wishes that should endure over years or even decades, writing them down in a letter can keep your wishes from fading with time.

Letters of intent are not legally binding. They offer trustees guidance and information, but a trustee is not required by law to follow a letter of intent's suggestions. Trustees are free to use their judgment to make decisions for the best interest of the beneficiary, even if those decisions contradict the beneficiary's preferences, or the preferences of the beneficiary's parent or previous caregiver. If you decide to write a letter of intent and find that you want future trustees to be legally bound to make certain decisions on behalf of your loved one, see a special needs planning attorney for help. (See Chapter 11.)

How a Letter of Intent Helps

A letter of intent documents the information that is often lost when a main caregiver (often a parent and trustee of the special needs trust) dies or can no longer care for a trust beneficiary. The main caregiver for a person with special needs is often also that person's life-long advocate and decision maker, so when that caregiver becomes unavailable, critical information about caring for the person with special needs can be lost. Writing a letter of intent provides need-to-know information about caring for the person with special needs, so that a successor trustee can step in to make informed decisions.

When you write a letter of intent, you can include whatever information you feel would be relevant for a successor trustee to know about your loved one. The letter might include serious information, like a medical allergy or required treatment. Or it could be as simple as listing the beneficiary's favorite foods. It also might list which family members and friends should be allowed to visit and which should be avoided. Even when beneficiaries have the capacity to make their own decisions, a parent may still want to express some preference and limitations. Ultimately, the content of the letter is up to you.

In addition to information about the beneficiary, a letter of intent can provide guidance and instructions to a successor trustee about how to use the trust money. The trustee is often working with limited resources, and the trustee may be faced with difficult decisions about what to provide or not provide to the beneficiary to meet his or her daily needs. The trustee could also face questions about whether to make large disbursements for specific expenses (like a new therapy that shows promise) or whether the funds should be kept in the trust for later needs. A letter of intent can help a trustee make these tough decisions when the letter shares what the beneficiary's parent or former caretaker would do.

Tips for Writing a Letter of Intent

- Parents, brothers, sisters, other family members, and especially your loved one with special needs can contribute to the letter.
- The contents of the letter should reflect your wishes, without laying out demands. Future circumstances may make it difficult for others to carry out strict instructions. You must trust that those carrying out your plan will try to adhere to your expectations.
- Gear the preferences in the letter toward enhancing your loved one's independence and growth.
- Put your loved one's needs first; try to prioritize your loved one's needs over the convenience of others.
- Write the letter in your own personal style, avoiding technical language when possible. Use the letter to communicate your heartfelt desires.
- While a letter of intent is not legally binding, its contents should not contradict your trust. Provide a copy of your letter to your attorney (if you have one), so that he or she can check to make sure that it is consistent with the terms of your trust.

EXAMPLE 1: Julie is a 30-year-old with a rare genetic disorder that does not allow her to speak or communicate. Her mother recently died and Julie lives in a board and care facility. Her mother set up a special needs trust that exceeds $200,000. Julie's cousin Brian was named trustee of her trust because he is around Julie's age. Brian lives several states away and has not spent a lot of time with Julie. Upon funding the trust, several family members confront Brian about paying for them to come and visit Julie. Julie's board and care facility is demanding that Brian pay them for therapies that Julie is receiving, and are seeking to raise her monthly payment by a $1000. Further, another family member is asking Brian to fund a $40,000 therapy that could give Julie a chance to communicate.

Brian wants to do a good job but he does not know where to turn. The trust document does not provide detail how to spend trust funds, but Julie's mother also wrote a letter of intent. In it, she explains that Julie should not visit the relatives who are demanding compensation (or have them visit her), as they have said hurtful things to the mother about Julie's condition and they have never helped with Julie's care. The letter goes on to explain that Julie's board and care is notorious for seeking payment for services it does not render. She has had to fight them over this many times, and she included the name of an attorney she has used to fight the facility. The letter of intent ends with a description of the various therapies they had tried for Julie over the years. Included in that list was the therapy proposed by the other family member, and it was unsuccessful.

Armed with this knowledge, Brian refuses to pay for the relatives to visit, rejects the distribution for the therapy, and hires the attorney to advocate on Julie's behalf with the board and care facility. Without the letter of intent, he would not have known the proper course to take.

EXAMPLE 2: Johnny, a 28-year-old former athlete with paraplegia, wants to climb the famed El Capitan monolith in Yosemite National Park. The cost, including paying a highly skilled fellow climber and renting lots of special equipment, will exceed $50,000.

Johnny's special needs trust currently contains assets worth $150,000, which were placed in the trust from Johnny's mother's will. Matthew, the person serving as trustee, has computed a rough budget of $10,000 a year. Matthew is concerned at spending one-third of Johnny's trust fund—and five times the annual budget—on one event, especially because Johnny may live another 50 years and will undoubtedly have many special needs over that period of time. Matthew is undecided on how best to handle Johnny's request.

Fortunately, Johnny's mother left a letter of intent. In it, she describes how she wants to support Johnny's lifelong dream to climb El Capitan, and that she would fully support spending money to do so. Matthew agrees to the distribution.

In this example, Johnny's mother could also have said that she wants to preserve the money in this trust for his lifetime needs, and that she would not support spending substantial amounts of money on one trip. Had she done so, Matthew might have made a different decision. However, in either case, Matthew has full discretion to make whatever decision he feels is in Johnny's best interest—even if such a decision directly contradicts the statements made in a letter of intent. That said, a trustee does have responsibility to comply with the intent of the people who established the trust. So if the trustee refuses to follow an instruction in a letter of intent, he or she must have a good explanation why it is in the beneficiary's best interest to do so.

Before You Write Your Letter

Drafting a letter of intent can be difficult. It takes time, it may bring up difficult memories, and information may change quickly. Take your time, and keep in mind that there is no right way or wrong way to prepare one; it is just important to have one.

There is no set number of pages you should write, nor is there an exhaustive or exact list of topics to cover. For some people, it's enough just to put together one page of names and addresses of the people who have knowledge of their loved one. At the other end of the spectrum, other people might write 50 pages covering every aspect of their loved one's life.

TIP

Try keeping a daily record of your loved one's needs. If you're having trouble figuring out what to include in your letter, try keeping a daily diary of your loved one's needs for a few weeks or months. Doing so will likely provide a thorough record of what a future trustee might need to know, and it might be less overwhelming than trying to think of everything in one sitting.

What to Include in Your Letter

Below is a list of some topics you can cover in your letter. Read it as a way to spark ideas about what to include in a letter that reflects your loved one's needs and circumstances. To view an example of a completed letter of intent, see Appendix B. You may wish to include:

- **Basic information.** Include basic information about your loved one. For example, his or her full name, date and place of birth, and Social Security number, as well as the name and date of the special needs trust.
- **Contact information for close friends and family.** Provide the names of and contact information for relatives who have a good relationship with the trust beneficiary. Describe how often the beneficiary sees them and what the visits are like.
- **Agencies.** List any agencies that relatives, trustees, and guardians should contact for advice and help. For example, include the local chapter of The ARC, law firms, case managers, care providers, physicians, and therapists.
- **Financial information.** List financial information that may be of use. This could include any government benefits the beneficiary receives or may be eligible to receive, and any arrangements with a corporate trustee, care manager, or other entity needed for continued care. Include the name and address, plus any special instructions.
- **Employment.** Note the jobs or volunteer positions your loved one has held. Also note any potential for employment, and the types of employment your loved one might like.
- **Education.** List specific courses and teachers that bear on the beneficiary's present abilities. Reflect on what types of educational opportunities might be possible in the future.
- **Living arrangements.** Describe the beneficiary's current living situation, and perhaps describe the living situation you anticipate for the future. For example, you can describe the type of living situation (live with a relative, or in a small group home, or an apartment with support), any preferences about location (such as the exact location or type of location), and any unique features (nonsmoking, religious adherence) that are relevant.

- **Day-to-day routines.** List favorite foods, daily and weekly appointments, and regular recreational activities.
- **Programs and services.** Provide schedule and contact information about school programs, day programs, sports programs, habilitation programs, or other programs and activities in which your loved one regularly participates. Also list any therapies or medical interventions that are needed, or may be needed, such as job training, speech therapy, or behavioral evaluations.
- **General medical history.** Explain your loved one's disability, how he or she has coped, and what you expect in the future.
- **Current medical care.** Describe your loved one's routine medical care and offer your opinions about whether it is appropriate or could be improved. List the contact information for doctors and other health care providers, including physical or occupational therapists.
- **Health insurance.** List any health insurance that should be maintained, including addresses, phone numbers, and insurance policy number. Make a copy of any insurance cards and attach them to the letter.
- **Personal preferences.** Provide some information about your loved one's personal interests and inclinations. For example, you could describe favorite clothes or personal care products, likes and dislikes about food, chores, and other routine daily activities, or favorite personal items (like an iPad, a pet, or a blanket). Also describe any personal habits that it would be important for someone else to know about.
- **Recreation.** List any favorite recreation and other leisure activities, including their frequency and the level of independence your loved one experiences while doing them.
- **Social environment.** Describe relationships with friends and acquaintances.
- **Religious proclivities.** Offer a religious history, including contact information for any religious leaders with whom the beneficiary has a relationship.
- **Abilities.** Provide information about your loved one's level of independence for getting around the community. For example, explain any ability to ride public transportation, independence in shopping, and ability to go out alone. Describe your loved one's ability to handle money, as well as his or her ability to read, write, communicate, and comprehend communications from others.

- **Preferences for funeral arrangements.** Give some thought to what you want to happen when the beneficiary dies. Do you have a preference about what kind of funeral to have, or whether you'd want a burial or cremation? How much money do you want the trustee to spend on funeral arrangements?
- **Beneficiary's estate planning or legal documents.** If your loved one has prepared his or her own estate planning documents, it might be a good idea to provide information about those documents, along with information about who is serving as the person's agent for financial or health care decisions. Also, if the person has a guardianship or conservatorship, identify the case name, county of origin, case number, and who is the legal representative.
- **Other relevant information.** Describe any aspects of your loved one's disability that you feel are particularly important to understand. For example, provide details if your loved one needs a structured environment, needs to be kept away from food, or becomes upset at loud noises.

After You Write Your Letter

When you've finished your letter, give a copy to anyone who may be responsible for decisions about the beneficiary, including the successor trustee. Or, attach the letter to the original special needs trust document so that it will be easily available to the successor trustee when the time comes.

To make sure that the letter is up to date and reflects your loved one's current reality, schedule a regular time to review and update it. For example, you could review the letter on your loved one's birthday each year. Is there a new primary care physician, a new address, a new therapy? Things change and your letter of intent should keep up. Remember to provide updates to anyone who has a copy.